

Dying in America

Improving Quality and Honoring Individual Preferences Near the End of Life

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INSTITUTE OF MEDICINE

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Context

- In last century, death has evolved from a common family event centered in the home to a medical event.
- Many die in circumstances that do not reflect their preferences or values.
- There is a growing population of elderly Americans with multiple chronic illness, functional limitations, and frailty.
- In 2030 estimated that 69 million will be over 65 years of age (up from 35 million in 2000).
- There is a growing cultural diversity, which makes it more important for clinicians to approach all patients as individuals, without assumptions about the care choices they might make.
- Aligning clinical practices, public policies, and personal preferences will become increasingly important.

Committee Statement of Task*

Current state of end of life care with respect to:

- Delivery of medical care and social supports
- Patient-family-provider communication of values and preferences
- Advance care planning
- Health care costs, financing, and reimbursement
- Education of health professionals, patients and loved ones, and the public at large

*Abbreviated version. Full statement of task in committee report.

Committee Expertise

- Aging
- Palliative care
- Hospice
- Pediatrics
- Mental health
- Spirituality
- Caregiving
- Finance
- Health administration
- Public engagement
- Legal studies
- Health disparities
- Ethics
- Health systems research

Committee Process

- Six committee meetings
- Literature review
- Three public meetings
 - Family caregiver experiences and needs
 - State programs and policies for individuals approaching death
 - Clinical ethics
 - Spiritual and religious needs near end of life
 - Legal issues regarding advance directives
 - Public testimony
- Site visits
- Commissioned papers
- On-line testimony

Key Areas for Findings and Recommendations

- Delivery of person-centered, family-oriented care
- Clinician-patient communication and advance care planning
- Professional education and development
- Policies and payment systems
- Public education and engagement

Delivery of Care

Key Findings

- People nearing the end of life often experience multiple transitions between health care settings, fragmenting care and creating burdens for patients and families.
- Demand for family caregiving is increasing.
- Palliative and hospice patients may live longer than similarly ill patients who do not receive such care.
- Timely referral to palliative care is often slow.

Delivery of Care Recommendation

Government health insurers and care delivery programs as well as private health insurers should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.

Delivery of Care Recommendation (continued)

Comprehensive care should

- be seamless, high-quality, integrated, patient-centered, family-oriented, and consistently accessible around the clock;
- consider the evolving physical, emotional, social, and spiritual needs of individuals approaching the end of life, as well as those of their family and/or caregivers;
- be competently delivered by professionals with appropriate expertise and training;
- include coordinated, efficient, and interoperable information transfer across all providers and all settings; and
- be consistent with individuals' values, goals, and informed preferences.

Delivery of Care Recommendation (continued)

Health care delivery organizations should take the following steps to provide comprehensive care:

- All people with advanced serious illness should have access to skilled palliative care or, when appropriate, hospice care in all settings where they receive care.
- Palliative care should encompass access to an interdisciplinary palliative care team, including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, together with other health professionals as needed.
- Care should be characterized by transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system related to end-of-life care. The committee believes that informed individual choices should be honored, including the right to decline medical or social services.

Communication and Advance Care Planning

Key Findings

- Most near the end of life not able to make decisions about care – making advance care planning essential.
- Most who indicate preferences choose care focused on alleviative pain. However, because default of treatment is acute care, advance planning and medical orders needed to ensure preferences are honored.
- Frequent conversations between clinicians and patients necessary to avoid unwanted care.
- Incentives, quality standards and system support needed to promote improved communication between clinicians and patients.

Communication and Advance Care Planning Recommendation

Professional societies and other organizations that establish quality standards should develop standards for clinician-patient communication and advance care planning that are measurable, actionable, and evidence based. These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies. Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality.

Communication and Advance Care Planning Recommendation (continued)

Payers should tie such standards to reimbursement, and professional societies should adopt policies that facilitate tying the standards to reimbursement, licensing, and credentialing to encourage

- all individuals to have the opportunity to participate actively in their health care decision making throughout their lives and as they approach death, and receive medical and related social services consistent with their values, goals, and informed preferences;
- clinicians to initiate high-quality conversations about advance care planning, integrate the results of these conversations into the ongoing care plans of patients; and
- clinicians to continue to revisit advance care planning discussions with their patients because individuals' preferences and circumstances may change over time.

Professional Education and Development

Key Findings

- The establishment of specialty practice in hospice and palliative medicine is a major improvement in the education of health professionals.
- Three problems remain: (1) insufficient attention to palliative care in medical and nursing school curricula; (2) educational silos that impede the development of interprofessional teams; and (3) deficits in equipping physicians with sufficient communication skills.
- Health professionals are not always adequately prepared to deliver care to patients who are not currently hospitalized or do not require specialty palliative care.

Professional Education and Development Recommendation

Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.

Professional Education and Development Recommendation (continued)

Specifically,

- all clinicians who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management;
- educational institutions and professional societies should provide training in palliative care domains throughout the professional's career;
- accrediting organizations should require palliative care education and clinical experience in programs for all specialties responsible for managing advanced serious illness;

Professional Education and Development Recommendation (continued)

- certifying bodies and health systems should require knowledge, skills, and competency in palliative care;
- state regulatory agencies should include education and training in palliative care in licensure requirements for professionals who provide health care to those nearing the end of life;
- entities that certify specialty-level health care providers should create pathways to certification that increase the number of health care professionals who pursue specialty-level palliative care training; and
- health care delivery organizations, academic medical centers, and teaching hospitals that sponsor specialty-level training positions should commit institutional resources to increasing the number of available training positions for specialty-level palliative care.

Policies and Payment Systems

Key Findings

- Incentives under fee-for-service Medicare result in more use of services, more transitions among care settings, and late enrollment in hospice, which jeopardize the quality of end-of-life care and add to its costs.
- Programs that integrate health care and long-term social services may reduce hospitalizations and health care costs while improving patients' quality of life.
- Palliative care services, including hospice, improve patient outcomes and may reduce health care costs by lessening use of acute care services.
- Quality standards and measures are needed to ensure that changes in payment systems, do not adversely affect quality of care for patients at the end of life.

Policies and Payment Systems Recommendation

Federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life. To the extent that additional legislation is necessary to implement this recommendation, the administration should seek and Congress should enact such legislation. In addition, the federal government should require public reporting on quality measures, outcomes, and costs regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers (e.g., Medicare, Medicaid, the Department of Veterans Affairs). The federal government should encourage all other payment and health care delivery systems to do the same.

Policies and Payment Systems Recommendation (continued)

Specifically, actions should

- provide financial incentives for
 - medical and social support services that decrease the need for emergency room and acute care services,
 - coordination of care across settings and providers, and
 - improved shared decision making and advance care planning;
- require the use of electronic health records that incorporate advance care planning to improve communication of individuals' wishes across time, settings, and providers; and
- encourage states to develop and implement a Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements.

Policies and Payment Systems Recommendation (continued)

Medical and social services provided should accord with a person's values, goals, informed preferences, condition, circumstances, and needs, with the expectation that individual service needs and intensity will change over time. High-quality, comprehensive, person-centered, and family-oriented care will help reduce preventable crises that lead to repeated use of 911 calls, emergency department visits, and hospital admissions, and if implemented appropriately, should contribute to stabilizing aggregate societal expenditures for medical and related social services and potentially lowering them over time.

Public Education and Engagement

Key Findings

- Not only do most Americans lack knowledge about end-of-life care choices, but the health community and other leaders also have not fully utilized strategies to make that knowledge available, meaningful, and relevant across diverse population groups.
- Efforts are needed to normalize conversations about death and dying.
- Several social trends suggest that the time is right for a national dialogue on this issue, including health care consumers' motivation to pursue high-quality care for themselves and their loved ones.

Public Education and Engagement Recommendation

Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

Public Education and Engagement Recommendation (continued)

Specifically, these organizations and groups should

- use appropriate media and other channels to reach their audiences, including underserved populations;
- provide evidence-based information about care options and informed decision making regarding treatment and care;
- encourage meaningful dialogue among individuals and their families and caregivers, clergy, and clinicians about values, care goals, and preferences related to advanced serious illness; and
- dispel misinformation that may impede informed decision making and public support for health system and policy reform regarding care near the end of life.

Public Education and Engagement Recommendation (continued)

In addition,

- health care delivery organizations should provide information and materials about care near the end of life as part of their practices;
- government agencies and payers should undertake, support, and share communication and behavioral research aimed at assessing public perceptions and actions with respect to end-of-life care, developing and testing effective messages and tailoring them to appropriate audience segments, and measuring progress and results; and
- health care professional societies should prepare educational materials and encourage their members to engage patients and their caregivers and families in advance care planning, including end-of-life discussions and decisions.

Conclusion

The committee identified persistent major gaps in care near the end of life that require urgent attention from numerous stakeholder groups.

The committee believes a patient-centered, family-oriented approach to care near the end of life should be a high national priority and that compassionate, affordable, and effective care for these patients is an achievable goal.

Report and Dissemination

- Report available: www.nap.edu
- IOM will engage in 12 month dissemination phase. Elements for dissemination:
 - Developing materials
 - Engaging relevant stakeholders and key audiences
 - Evaluating tactics to inform future activities

